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Counting Us In: Problems and Opportunities in Health Research on Transgender and Gender-Nonconforming Communities

Christoph Hanssmann[1]

INTRODUCTION

In the last decade, the emergence into the public consciousness of transgender as an identity and as a field of study has had a profound impact on individuals who claim, or are incorporated in some way, by the term "transgender." This shift has resulted in an increase in the degree to which public health research incorporates questions about transgender health. The past several years have seen a rise in the number of epidemiological studies and reviews concerning transgender individuals.[2] These findings are being taken up in the work of activists and policymakers. While this may be considered a success in terms of gaining empirical evidence to ground claims for increased access to health and social services and to support initiatives that reduce health disparities among transgender and gender-nonconforming individuals, it may also carry a number of problematic implications.

This article examines the context of the emergence of increased demands for trans health research and practice and argues that simple inclusion in most existing frameworks of health research and biomedicine will not yield a broadly effective result. Health research in other marginalized health-based projects, such as HIV/AIDS research in gay men's health, has taken some missteps that we may take care to avoid in navigating a path that is more constructive and efficacious for the health and wellbeing of trans gender-nonconforming populations. Doing so necessitates a critique of the following: the professionalization of trans health advocacy in the context of social movements' incorporation by nonprofits; a critique of state-based

violence and its effect on health outcomes, as well as the relationship of health research to state projects to increase criminalization and surveillance; and a critical examination of the role of health research and advocacy in reifying narrow identity categories that erase the complex experiences and multiple vectors of oppression faced by trans populations.

This article will explore several questions in an effort to shed light on areas of tension and ambivalence with regard to transgender inclusion in health research:

1. In what ways do the foci of epidemiological studies (frequently, the risk of violence or HIV infection) frame the ways these studies are discussed and used as a basis for action?
2. What is the significance of including transgender individuals in health research, and what is at stake in doing so?
3. How does the category of "transgender," as it is mobilized in epidemiological research, obscure and complicate issues relating to other factors of marginalization and social determinants of health?
4. How do epidemiological data and inclusion, or exclusion from health research in general, "loop back"[3] to affect transgender people's concepts of themselves as individuals and as members of trans communities?

While there is much articulated resistance in transgender and gender-nonconforming communities to the pathologizing research that dominated in the past,[4] there is palpable enthusiasm for more current models of health research in general and epidemiological and pharmacological health research in particular. The reasons for this support are many and are generally quite valid. For example, some transgender and gender-nonconforming people pursue specific medical interventions that have not been well evaluated with regard to efficacy and potential risks.[5] Additionally, groups involved in trans activism and advocacy, as well those involved in research, have grown in number and scope. Now that we may, in some instances, influence research agendas, can we not drive their

direction in ways that will be supportive of our communities and of our health and wellbeing?

I begin this article with an assumption that trans health is important and valid, that all transgender and gender-nonconforming people are entitled to exceptional healthcare that offers access to good health to whatever extent possible inclusive of gender-confirming and supportive care, and that none of us should encounter barriers to primary or specialty medical care that we require. Additionally, I assume that health research, in general, is an important pursuit that transgender and gender-nonconforming people can benefit from. However, I also intend to issue certain cautions about how this research is pursued and positioned, and I warn that this work must be organized in such a way as to attend to the lopsided distribution of benefits and uneven vulnerability on the part of certain populations of trans people, such as trans people of color and poor trans people, rather than focus only on certain sectors of these communities with greater relative privilege.

I. Shifts in Approach: Health Research on Trans and LGBTQ Communities

In the past several years, there has been a marked increase in the number of epidemiologic and other health research studies that concern transgender individuals.[6] Many of these studies differ significantly in content and approach from medical studies of transsexuals[7] conducted in the early- to mid-twentieth century.[8] In general, the literature on transgender health that is currently available focuses on health disparities, disease prevalence and incidence, and particular associations of trans identity with negative health outcomes (such as experience of violence). This contrasts with earlier studies that explored the etiology of transsexuality itself, and its relationship to, or overlap with, homosexuality.[9] In other words, these studies have shifted from focusing on a *disease* to focusing on a *community*.

As far as we know, these earlier studies were conducted strictly by non-trans psychiatrists, sexologists, and physicians. In contrast, one feature of

this new wave of trans health research is that in some cases, transgender or gender-nonconforming individuals are directly involved in the design, implementation, and dissemination of these studies.[10] Many serve as principal investigators, researchers, and medical doctors. To a growing degree, trans individuals are seen as experts within our own communities.[11]

A. Trans Health in the Context of LGBTQ Health Advocacy

LGBTQ health has recently taken shape as a unique form of health activism within the United States. Trans health advocacy has emerged as a distinctly marginal aspect of this project. While at times it has claimed distinct needs,[12] trans health advocacy is frequently subsumed within "LGBTQ health."[13] As Steven Epstein has noted, LGBTQ health advocacy initially took shape within grassroots activism. Its origins were in the feminist women's health movement and in the approaches that the group ACT UP (a radical grassroots group formed in response to the AIDS crisis) initially took in targeting federal biomedical institutions.[14] Early LGBTQ health activism targeted pervasive homophobia in clinical settings and the lack of attention political leaders gave to the effect of AIDS on LGBTQ communities. Gradually, as activists gained greater membership as what Epstein calls "lay experts" and "treatment activists," (or activists who gained knowledge about biomedical research for the purpose of influencing the decisions of researchers and other powerful stakeholders) and as increased resources were earmarked for pharmacological and health research on HIV/AIDS, objectives shifted.[15]

Epstein discusses some of the tactics of grassroots community-based health activism of the early 1990s, including the formation of locally-based organizations dedicated to service provision, education, and prevention and engagement in militant direction action projects, street activism and self-education. He traces several departures from these tactics toward a state-based focus on improving the health status of LGBTQ communities.[16] Calls to national membership organizations—like the Gay and Lesbian Task

Force—to adopt an LGBTQ health agenda as well as greater involvement of lesbians in cancer prevention and research—breast cancer, in particular, as an area of interest—with special focus on groups like the National Cancer Institute, are both examples of state-based health activism.[17] In addition, he notes, LGBTQ physicians began to rally for shifts from within the medical establishment. First formed as the American Association for Physicians for Human Rights, this group was later renamed the Gay and Lesbian Medical Association (GLMA).[18] In 1996, GLMA added bisexual and transgender health to its list of concerns.[19]

In this shift to state-based health activism, the focus on LGBTQ health moved from community-based concerns about homophobia in clinical settings to broader health disparities,[20] with particular attention to the increased burden of disease and disease risk (AIDS/HIV, cancer, tobacco use, cardiovascular disease, and a variety of others) in these communities when compared to other social groups.[21] Concurring with this change in focus was a change in agenda: broad epidemiologic research became a primary objective of LGBTQ health activism.[22] This was seen as important both in empirically establishing widespread health disparities and in the resulting evidence being available for use in leveraging resources to cultivate health and prevent disease in these communities.[23]

With this shift in LGBTQ health has come some degree of incorporation and institutionalization within national health research agendas. For example, GLMA published a compendium to the report, *Healthy People 2010*, which focused on LGBTQ health disparities and areas for continued research.[24] In 1998 and 1999, the American Public Health association passed two resolutions calling for increased inclusion of LGBTQ people (in 1998) and transgender individuals in particular (in 1999) in health research.[25]

While transgender communities are included in this work, our needs and concerns are frequently sidelined, particularly as it becomes more broadly institutionalized. Federal officials, it is assumed, find categories such as

transgender "too 'out there,'"[26] and resist making changes to entrenched methods of data gathering, such as including demographic options that are not restricted to male or female.[27] This parallels some of the ways that trans communities have been left out of a variety of state-based initiatives. For example, the Employment Non-Discrimination Act (ENDA) is a federal legislative bill that seeks to protect employees from being fired on the basis of sexual orientation or gender identity (the latter of which was only added to the bill's language in 2007, after its initial introduction in 1994).[28] In 2007, the year the bill was passed by the House, "gender identity" was eliminated for fear that it would not pass if it protected more than just sexual orientation.[29]

Trans and LGBTQ movements are often closely tied, "in part because United States culture often conflates sexual orientation and gender expression, and in part because of a long history of sexual and gender outsiders finding community together, resisting oppression together, and often understanding their identities through and against each other."[30]

There is some ambivalence about the relationship between emerging trans struggles and LGBTQ activism, particularly mainstream advocacy projects that are characterized by the pursuit of state inclusion such as gay marriage and participation in the military. Trans and gender-nonconforming people face concerns that differ somewhat from the concerns faced by gender-conforming LGBTQ people. These unique concerns, combined with the hesitancy of state-based projects to include transgender and gender-nonconforming people, have caused trans activists and advocates to pursue trans-specific research and initiatives.

B. Trans Health Advocacy as a Unique Pursuit

As trans health advocacy emerges as a pursuit separate and unique from LGBTQ health advocacy, individuals in trans communities are increasingly calling for more health research, regardless of the barriers to inclusion within broad-based federal research programs. For some, this is noteworthy

because it indicates a shift away from distrust of the biomedical establishment, which continues to play a particularly insidious role in the lives of many trans individuals, exercising coercive and rigorous gate-keeping practices in managing patients' gender transitions, and acting as an authority in establishing trans identities as strictly medicalized. Much trans activism is based in a critique of medicalization because:

1. Physicians are seen as the ultimate authority on a person's gender identity, above and beyond a person's self-identification
2. The pathologization of the category of trans stabilizes non-trans identity as non-pathological
3. Other vectors of oppression, such as class, race, age and ability figure into basic health care access, the lack of which may have negative implications in healthcare providers making diagnoses concerning trans identity
4. The law has incorporated a medicalized model of trans identity that affects trans people's ability to obtain essential legal documents, such as identification, unless they have "proof" of medically-validated trans identity.

However, it is possible that the earlier described shift of transgender and gender-nonconforming people taking a greater role in medicine and health research has made biomedicine more responsive, in limited instances, to the needs of these communities.

1. Specific Issues Related to Trans Health Research

Similar to LGBTQ health activism, calls for trans health research focus on exploring the existence and pervasiveness of health disparities among transgender and gender-nonconforming communities.[31] This is necessary to gain a better understanding of how to mitigate the effects of these inequities and to build broader and more effective interventions to meet these goals.

However, there are several reasons that trans health distinguishes itself from LGBQ health advocacy and investigates disparities through the lens of

trans identity specifically. Epidemiologic research may focus on some similar health outcomes and disproportionate disease burden,[32] but researchers assume that risk factors differ in various ways. In addition, some transgender and gender-nonconforming health advocates are interested in health research that departs from concerns of gender-conforming LGBQ populations. For example, some transgender and gender-nonconforming individuals may pursue gender-confirming medical interventions, such as hormone treatment or surgeries, and these require both specific research and clinical competencies.[33] Last, the medical profession views transgender as a "condition" or a clinical diagnosis in ways that are not the case with regard to sexual orientation.[34] This contextualizes and positions trans health activism and research in ways that differ from how LGBQ health activism has positioned itself.

For example, in contrast to non-trans-LGBQ communities, there is great interest in pharmacological research on the long-term effects of masculinizing or feminizing hormones,[35] although I will not explore this topic in-depth in the context of this article. This topic merits its own exploration of the economies of pharmaceutical research and marginalized populations in the context of biomedicine. There is also a great deal of interest in incidence and prevalence of HIV/AIDS in transgender and gender-nonconforming populations, particularly given the recent high rates that have been documented among trans women in metropolitan areas.[36] These and other issues illustrate the ways in which trans health advocacy is concerned with the potential differences in risk factors and health outcomes that set it apart from LGBQ health advocacy in general.

2. Trans health Research: How LGBTQ Health Advocacy Shaped Priorities

a) Topical and Methodological Foci

Despite some of the ways trans health activism and research has become distinct from LGBTQ health advocacy, it carries vestiges of its growth from within this context. Trans health research agendas have been articulated from a variety of contexts, ranging from state-based[37] to community-engaged.[38] It is important to consider how these distinct agendas emerged and what the consequences are of following the state-based research trajectories of LGBTQ health advocacy, both of which I will attend to in the next section. In the context of this article, "state-based" strategies are those that aim to improve population health outcomes spanning broad and geographically dispersed groups of people. Strategies may be in the form of federal programs, legislation, state mandates, large-set data collection and quantitative analysis, and so on. "Community-based" strategies, in contrast, are generally local to smaller geographic areas and population subsets. These may be smaller-scale policy-based projects, targeted interventions, or research focusing on more in-depth data collection and/or smaller or more specific datasets.

It is likely that some of the focus on HIV/AIDS as a trans health issue emerged in part because of trans health originating in part from LGBTQ health advocacy more broadly. From within state funded and administered research programs in the area of HIV/AIDS, the issue of disproportionate disease burden for trans people emerged.[39] However, the Centers for Disease Control (CDC), the primary federal body in charge of disease surveillance in the United States, failed in their epidemiologic data gathering to distinguish between "men who have sex with men" (MSM) and trans women who have sex with men, lumping both groups into the MSM category.[40] Thus, HIV/AIDS as a trans health concern was subsumed within gay and bisexual men's health. Notably, trans men who have sex with other men (trans or non-trans) did not specifically figure into data collection as MSM.

Noting this error in conceptual conflation on the part of the CDC, some researchers and trans health activists set out to establish disparities in health

outcomes with regard to HIV/AIDS incidence and prevalence rates as distinct from patterns in gay and bisexual non-trans men (or MSM more broadly).[41] Disease incidence and prevalence patterns are also linked to funding allotment for prevention efforts, and given researchers' assertions that funding streams directed towards prevention efforts for MSM do not address the needs of transgender individuals,[42] activists and researchers prioritized establishing a body of data to demonstrate HIV/AIDS as a specific issue within trans communities.

This paved the way for a variety of small-scale epidemiologic studies to track HIV incidence and prevalence rates in trans communities. These concerned trans women, though more recent studies have also investigated HIV/AIDS incidence and prevalence, as well as risk factors, among trans masculine individuals.[43]

Some of these studies were conducted in collaboration with transgender and gender-nonconforming communities.[44] Community-based participatory health methods, which I will discuss in more detail later in the article, also use epidemiologic approaches to gathering information about disease burden in communities. However, they do so in a way that puts stake in local and community knowledge about context and underlying causes. These projects engage academically unaffiliated community members in the process of developing and advancing topics to pursue in health research.[45] In general, community-based studies have tended to undertake multi-layered investigations of HIV/AIDS incidence and prevalence as one of many factors affecting trans health and its occurrence in the context of other factors affecting health (e.g., lack of access to employment or housing leading to survival sex work).

This approach contrasts with traditional research methods that assume scientific experts are best positioned to discern the reasons for disease and to design interventions for prevention. While most HIV/AIDS and health research has taken a traditional approach, notable exceptions have produced nuanced understandings of health inequities in trans and gender-

nonconforming communities and rich descriptions of the context in which these occur. They also focus on some of the important differences among individuals within trans communities and how these make a difference in health outcome.

In some ways, research on HIV/AIDS in trans communities has seen an overlapping of state-based agendas with community-based research. Researchers with the former orientation have used traditional epidemiologic data gathering that has emerged from national surveillance programs to a similar end—to secure funding and design interventions. Researchers with the latter orientation have employed different methods but with a similar topical focus on HIV/AIDS, which initially emerged and gained momentum from state-based research agendas. This tension highlights some of the broader questions about trans health in relation to LGBTQ health: how does trans health go about articulating a different approach to health research and also begin to develop its own complex topical foci when its history is so intertwined with that of LGBTQ health? What might we learn from the direction of LGBTQ health advocacy?

b) Funding Structure, Professionalization, and the Turn Away from Community-Based Work

The relationship between movements and funding is important when considering the factors that frame health research and the disparities to leverage funding. Nonprofit agencies and nongovernmental agencies have, in the past several decades, grown to supplant the previous role of state-based public benefits programs that grew from the New Deal.[46] Named the "shadow state" by Jennifer Wolch,[47] this move has created the context for a shift in the realm of activism into what many critics have called the "nonprofit industrial complex."[48] This has been the source of many fissures within activist communities and has been criticized in particular for its move towards professionalization and its turn away from grassroots models of activism.[49] One problematic feature of this transition in activism is the

degree to which the viability of projects is linked to palatability. This link is evaluated by private and governmental funders, rather than the urgency or priority determined by affected members of the communities the projects are designed to serve.[50]

Similar to Epstein's articulation of the shift from a community-based LGBTQ health movement to one focused on state-based research agendas, mainstream gay and lesbian politics in the past two decades have become increasingly focused on state legislative goals over grassroots community-based organizing.[51] This move has created a situation, as Manazala and Spade outline, of social movements becoming more reliant on corporations and on foundations with accumulated wealth, and, through a process of co-optation, gay and lesbian rights work has tended increasingly towards work protecting individual rights of property over collective wellbeing.[52]

These trends of professionalization and cooptation have impacted health advocacy, causing HIV/AIDS to come to define gay health in the 1980s and 1990s, much to the detriment of gay health advocates in establishing a broad and far-reaching health program.[53]

As trans and gender-nonconforming health activists set priorities for trans health, it is important to consider some of the ways that issues at a federal level may not align directly with the priorities of local trans and gender-nonconforming communities, particularly since these communities differ radically along lines of race, ethnicity, class, nation of origin, immigrant status, age, sexual orientation, ability, religion, geographic location, and so on. Instead, an expanded focus on community-based health research projects may have a greater potential to attend to the particular local needs of trans and gender-nonconforming communities, given the disparate and differing needs within these populations. Without the capacity for complexity, flexibility and geographic specificity allowed by more deeply focused and localized research, it is likely that research projects will fix upon a less nuanced set of analyses within this population, possibly consolidating relative benefit among those with the most relative privilege.

II. Achievements and Concessions of Trans Inclusion in Health Research

There have been a variety of achievements in recent years related to trans inclusion in health activism and research. These include recent (though not broadly incorporated) recognition of the need for health insurance coverage for trans-specific healthcare treatments and the expansion of trans health as an area for investigation within community-based research. However, with achievements often come concessions, and I will point out areas where trans inclusion in health research could benefit from a thorough examination of its goals and a reassessment of some of its current trajectories.

In 2008, the American Medical Association passed Resolution 122 entitled "Removing Barriers to Care for Transgender Patients." It reads, "Resolved, that our American Medical Association support public and private health insurance coverage for treatment of gender identity disorder as recommended by the patient's physician."[54] While the resolution maintains the restrictive and coercive structure that trans and gender-nonconforming people in the United States must navigate,[55] it is a significant victory in the effort to reduce barriers to trans healthcare. As gender-confirming medical interventions for trans people have remained largely uncovered by public benefits programs and private insurance companies, those individuals who seek hormone and surgical treatments have, barring significant access to wealth, found many of these to be out of reach.[56] The AMA resolution does nothing to disentangle the complex and contradictory network that trans and gender-nonconforming people are subject to with regard to legal identification, gender segregated facilities, and other sources of anxiety, frustration, and lack of safety.[57] However, if taken up in medical practice, it may do a great deal to remove an important barrier to healthcare for many trans and gender-nonconforming individuals. The ultimate effectiveness of the resolution remains to be seen, but it may be indicative of the direction in which medical practice is moving.

More recent needs-assessment studies have helped increase the body of knowledge about trans and gender-nonconforming health concerns and needs. These studies are in addition to research studies that focus solely on HIV/AIDS incidence and prevalence and are an achievement in establishing some of the widespread barriers to health that trans and gender-nonconforming people regularly encounter.[58] These have served both to highlight pressing problems and needs within trans and gender-nonconforming communities, as well as capture data about health status and areas for further research within these populations. Most of these studies document issues related to employment and housing access, barriers to high-quality primary and medical care, and exposure to transphobic violence. These findings can help ground claims for improved access to health and social services, and document the pervasiveness of barriers to health and wellbeing for many individuals. It is likely that these studies have played a role in establishing the body of knowledge that set into motion broad policy decisions such as the AMA resolution described above. In addition, such evidence is currently used to justify the development of trans-specific agencies, services, and other community-based projects.[59]

Despite these important gains, there remain issues which have not been attended to thoroughly in conceiving a model for trans health with the potential to transform and support the health and wellbeing of trans and gender-nonconforming communities. First, we must exercise caution in how we use the term "transgender" as a category, and how it might collapse important differences within it. We also must remain cognizant of who might be left out in the choice to use this particular term. For example, "transgender" is a category that has varying degrees of resonance among those incorporated within the term, and identification with the term may vary along racial and class lines.[60] In addition, people without access to race, class, and education privilege are likely to encounter more severe and frequent barriers to health than those with greater access. These differences may be obscured or attenuated in the context of health research that

considers transgender people overall. Gender-nonconforming individuals who are not necessarily included as "transgender" (either based on self-identification or research criteria), but who face similar or related obstacles to positive health outcomes, may be excluded from consideration.

Second, we must consider whether the questions we ask and the answers we seek are necessarily shaped by the context in which we ask them. The ways in which epidemiologic, health, and pharmacologic research moves from a certain set of assumptions about what questions matter—and indeed, what knowledge is valuable or useful—works to prioritize certain answers and ways of knowing. As Nancy Krieger asserts, epidemiology is, like any science, at once objective (using defined, rigorous, and replicable methods to assess refutable propositions) and partisan (reflecting underlying values and assumptions guiding conceptualization, choice, and analysis of research problems).[61]

Marj Plumb notes that "what is knowable about a population and its health conditions cannot be found solely through quantitative science," and that local knowledges are frequently viewed "by scientists as unreliable, biased, and politically motivated."[62] The investment in professionalization, expertise, and empirical data at the expense of community-based, local, and anecdotal knowledges serves to shift credibility away from local knowledge. Although, at this point, some professionals and experts are indeed members of trans and gender-nonconforming communities, this change has not collapsed divisions in access to various types of privilege that separate "experts" from "laypeople."

Health research in trans and gender-nonconforming populations takes place within this set of tensions. As "transgender" is a provisional, contextual, and mutable term to describe identity and experience, it is challenging to gather meaningful data using it as a stable analytic category. Given the legacy of biomedicine with regard to its frequent conceptualizations of gender-nonconformity as pathological, it is crucial to consider Krieger's assertions about the partisan aspects of epidemiology.

There is surely valuable information to be gained in and through health research in trans and gender-nonconforming populations, However, there are a set of underlying values and assumptions that guide choices about how research questions are framed, how inclusion and exclusion criteria are formulated, what variables should be considered, and what methodologies are utilized, and these questions frequently fade into the background. It is important that we grapple with these and other important questions as health research in trans and gender-nonconforming populations gains momentum. In addition, it is vital to remember that rich and valuable information (including information about health and wellbeing) is knowable through a variety of means separate from health research.

III. CURRENT TOPICS OF CONSIDERATION IN TRANS HEALTH RESEARCH

How we frame research questions matters, and so does the context from which we develop and pursue research agendas. If trans health activists are to follow LGBTQ health advocacy from community-based, local health activism to state-based research agendas, we are likely to miss asking questions that might yield answers that are critical of the state. In addition, it is useful to consider the ways in which research findings have been used so far and to speculate about how these may be applied in the future—either to the benefit or detriment of trans and gender-nonconforming people. Last, if we are to ask questions about the health and wellbeing of trans and gender-nonconforming people, we must attend to broader issues as well as narrow ones: for example, the way that the current structure of the U.S. healthcare system creates substantial barriers to trans and gender-nonconforming people accessing high-quality primary and specialty care.

Epidemiologic surveillance employs technology to monitor diseases and people at the population level, and uses differences between people to assess "risk," or a person's probability (based on group membership, environment, or other measured factors) to encounter or develop ill health.[63]

Trans health research, particularly epidemiologic research, has centered on topics that concern data that are broadly incorporated in programs of surveillance at the level of cities, counties, states, and nations. These topics generally fit within structures of state priorities in population management.[64] HIV/AIDS incidence and prevalence data and rates of interpersonal violence, for example, provide the basis for state policymaking about issues ranging from funding allocation to blood donation policies[65] to patterns of policing and criminal surveillance. Therefore, data collection, in establishing a concept of risk based on membership in a particular population, is used to support policies that have drastic effects on the lives of individuals based solely on their alignment with a certain group. However, health research in trans communities has conspicuously not paid attention to the state-based causes of disparities in health.[66] While interpersonal violence is a common topic of study within LGBTQ and transgender communities, gender-based violence that occurs in state-based institutions like jails and prisons, group homes, the military, immigration detention centers, and public benefits offices is rarely considered as a factor that is broadly detrimental to the health of trans and gender-nonconforming individuals.[67]

For example, transgender women of color are frequently profiled and targeted for being involved in sex work, and experience routine harassment and arrest as a result. Further, gender-segregated detention facilities usually result in trans women being placed in men's facilities, where they are in danger of violence and harassment by guards, staff, and other inmates.[68]

This inconsistency in considering interpersonal violence outside the context of institutional violence is also reflected in the ways policymakers and legislators draw on established data on violence. One particularly disturbing example is the way in which rates of interpersonal violence have been utilized by state apparatuses to advance hate crimes legislation.[69] Critiques of this legislation have centered on the ineffectiveness of these strategies in deterring violence. In addition, hate crimes legislation fails to

truly correct the problem, due to the expansion of the criminal justice system, which criminalizes trans people, particularly those that are already marginalized within trans communities, such as trans women of color.[70] Within the context of increased surveillance and criminalization, trans communities become even more vulnerable to police violence and surveillance. This demonstrates a tendency to address health problems with state-based solutions—to understand violence as a crime that ought to be punished through incarceration rather than to understand violence as a problem related to social inequities that might be dealt with at a community level. At a policy level, it demonstrates the ways in which outcome-focused health research that fails to attend to social context and broad inequities can result in laws and policies that make the same omission. And again, it fails to attend to the relationships and parallels between interpersonal and institutional violence.

This pattern of addressing the material results of inequities rather than the source of the problem occurs elsewhere in state-based responses to health crises. For example, state-based responses to HIV/AIDS acknowledge it as a disease with a disproportionate impact on certain marginalized communities. However, the focus on disease treatment and management, rather than on the causes and context of disproportionate impact, such as poverty, unemployment and other forms of inequity in a context of racism, classism, sexism, and ableism. Prevention efforts frequently focus on behavior, rather than the contexts which give rise to the constraint of options for marginalized populations.

While research has certainly advanced a set of priorities in increasing access to primary and specialty healthcare and focused health interventions, it has failed to attend to some important issues. One issue is the way in which non-coverage of gender-confirming medical interventions for trans people is largely tied to the structure of the U.S. health system, comprised primarily of private, employer-based health coverage. Expanding coverage of these interventions for trans people is crucial within this system, but this

would not make a difference for trans people who are uninsured or underinsured. Without broad access to preventive, primary and specialty services, existing health care disparities, including those within trans and gender nonconforming populations along lines of race, class, geographic location and ability, will simply be exacerbated. Access to care for trans and gender-nonconforming people cannot be separated from the pressing need to increase access to healthcare in general.

However, these are often viewed as unrelated issues. The very AMA that issued Resolution 122 has long been an opponent of restructuring the U.S. health system and universalizing healthcare. In comments submitted to the Senate Finance Committee, the AMA stated its position against establishing a public option: "The introduction of a new public plan threatens to restrict patient choice by driving out private insurers, which currently provide coverage for nearly 70 percent of Americans."[71] This opposition to universal healthcare or expanded health coverage in the public sector severely limits the capacity for increased equitability in health. A shift toward universal health coverage in the United States could be a move in the direction of reducing or eliminating a variety of health disparities both within and outside of trans and gender-nonconforming communities that stem from lack of access to affordable, high-quality healthcare. At the same time, universal health coverage without trans healthcare could worsen current health outcomes in trans and gender-nonconforming populations. And trans health care without universal coverage will only meet the needs of a limited set of people within these populations. Health and policy research must investigate and propose means to ensure that these discussions about universal access and trans health advocacy proceed in tandem, and to ensure that trans health is understood as legitimate within a context of a universal healthcare system.

This section has explored how current foci of trans health research on interpersonal violence and HIV/AIDS has tended to garner more attention than other urgent issues, such as institutional violence and health policy

research on expansion of health coverage, to name just two examples. This is not to imply that HIV/AIDS and interpersonal violence are not real and important issues in trans and gender-nonconforming communities. They are, and these topics certainly warrant attention, consideration, and the development of strategies for reduction. However, claims that are made in the context of health research may obscure the ways in which other overlapping factors, such as experiences of racism, sexism, misdistribution of wealth, and so on, may increase the likelihood of individuals in trans and gender-nonconforming communities to encounter these issues.[72] For example, lack of access to education or employment (often in the context of racism, classism, and sexism) might increase a trans individual's vulnerability to homelessness. Gender-segregated shelter systems often refuse to house trans individuals based on gender identity or expression, and they also frequently enforce gendered dress codes or appearance.[73] In addition, homelessness increases the likelihood that trans people will experience interpersonal violence and institutional violence through profiling and detention or arrest.

The focus on experiences of disease, rather than shared, parallel, or interlocking experiences of marginalization[74] within and beyond the context of these communities, may serve to divert attention away from some of the underlying causes of such diseases or barriers to health. Health research, in this case, may be less productive in the form of large-scale dataset analysis and more productive as a set of community-engaged projects to identify and interrogate health barriers and develop initiatives that target the root causes of these barriers. This would likely make a more tangible and beneficial difference in the lives of trans and gender-nonconforming people than many of the current uses of large-scale epidemiological research projects, which are more apt to fuel policy decisions by the state that penalize transgender people for experiencing health outcomes as a consequence of social inequities. Alternatively, if large-scale epidemiological research projects could significantly grow their capacity to take up questions of social

inequities and social embeddedness, this research strategy coupled with findings from local community-engaged research projects, could do a great deal to influence policy more effectively.

IV. WHAT IS AT STAKE IN THE ACT OF RESEARCH INCLUSION?

To best foster and support the health of trans and gender-nonconforming communities, it is important that we understand the health-related issues that affect us and how we increase access and reduce barriers to healthcare. Health research may play an important role in this. However, it is important, before we issue an unconditional call for inclusion in research programs, to consider the hazards of certain approaches to health research. In this section, I will discuss some of the challenges of researching trans health in the context of transgender as a medicalized identity. I will also discuss some of the pitfalls of epidemiologic approaches, such as the dangers of surveillance, the problems with reductive categories of identity, and the ways in which health research may play a part in exacerbating marginalization.

In *Inclusion: The Politics of Difference in Medical Research,* Steven Epstein discusses the recent emergence in biomedical and pharmacological research of the "inclusion-and-difference" model.[75] He uses this term to describe the paradigmatic shift away from "one-size-fits-all" assumptions about population health and toward a notion of "special populations" that require inclusion (of women, of people of color, of children, and so on) in research and that warrant a particular scrutiny within research that takes these "differences" into account. Epstein critiques some of the ways in which these formations concretize and reify culturally-informed notions of difference as fundamental, essential, and biologically based.[76]

This reification and "biologization" of categories is particularly troubling because it simultaneously erases the sociopolitical context of identity and marginalization, and it also attempts to extract categories of identity and experience as independent and more or less separable variables.[77] Janet

Shim discusses the divergent conceptions of race held by people with cardiovascular disease (CVD) and epidemiologists studying this disease. On one hand, people of color with CVD described racial identities as intertwined and inseparable from other categories of lived experience and identity. On the other hand, epidemiologists found this inseparability to be scientifically problematic:

> The epidemiologists I interviewed . . . view the fluidity and sensitivity of racial categories to social and political forces as scientifically troubling—categories can appear, disappear, and change meaning in response to the vicissitudes of the social, cultural, and political moment. In epidemiology, demographic variables are most conveniently managed and least subject to measurement error or bias when they are stable and constant, and therefore replicable and comparable over time and from study to study.[78]

Given the ways in which race, class, and various other factors contextualize the experiences and barriers to heath of trans and gender-nonconforming people, it is unlikely that rich or meaningful conclusions about health status may be reached by attempting to extract each of these (and others) into a series of stable, independent variables. The "difference-and-inclusion" paradigm relies on these reductive notions of identity that fail to incorporate intersectional aspects of human experience and lived social realities.[79]

Further, as has been observed in non-trans gay, bisexual, and queer men's health advocacy, the centrality with which HIV/AIDS came to define GBQ men's health came at the cost of establishing broad and multi-layered notions of health and wellbeing in these communities.[80] Ideally, conducting research in concert with developing broad intersectional social and political projects will allow us to begin to document and establish discrepant barriers to access, and to highlight harms facing trans and gender-nonconforming populations.

Some researchers, such as those in social epidemiology or other types of research that value community engagement research, grapple with the social context and intersectionality of identity in approaching health research.[81] When discussing the process of defining "lesbian" for the sake of research, Marj Plumb argues that "until we know who 'we' are, it is going to be difficult, and rife with inaccuracy, to count us."[81] In fact, it is difficult to imagine a way to define "transgender" in the context of health research that would not be "rife with inaccuracy" and would not likely reinscribe divisions of relative privilege within trans and gender-nonconforming populations. Other modes of categorization or inquiry might capture important themes without organizing along lines of identity—for example, using qualitative in addition to quantitative methods, or structuring epidemiological investigations that begin "with lay observations of health effects."[82]

A second problem with enthusiastic endorsement of inclusion in health research is the issue of medicalization. This involves the ways in which medicine and medical expertise, in concert with law- and policymaking, take on the management of certain conditions, experiences, or identities.[83] Epstein discusses the ways in which activists have inadvertently become complicit in the medicalization of LGBQ and trans identities by making arguments for the validity of LGBT health.

The likely consequence of the association of health risk with identity categories (rather than with shared practices or shared oppression) is the reification and medicalization of those identities. This might not be so worrisome were it not for the long history within medicine of conceptualizing difference as pathology.[84]

For trans people in particular, this may be perilous territory because the very consolidation of trans identity as a medicalized identity may increase perceived legitimacy and access for those of us who access or want access to medical interventions to achieve our desired gender expression. However, this frequently comes at the expense of our own self-

determination and at the expense of options available to those trans individuals (who are likely the majority) that do not want or who cannot afford surgeries to realize a desired gender expression. Legal recognition and support in accessing fair treatment, services, or benefits, for example, is frequently limited to trans individuals who have identities consistent with a medical model through surgeries or other medical intervention.[85]

For some trans individuals, medicalization *does* ground identification with the category, but the degree to which this is true varies enormously. Further, we have already seen the ways in which pervasive medicalization has caused enormous damage to trans and gender-nonconforming individuals. Many policies that govern a person's recognition as trans for purposes of various government agencies require medical evidence of having had gender-affirming surgeries, even though these are not necessary or affordable for many or most trans individuals.[86] In addition, if surgeries are desired, individuals must comply with a long and complex set of psychiatric and medical evaluations and expectations to gain access.[87] Upon completion of these, trans individuals may access costly surgery. However, since many insurance policies do not broadly cover such procedures at this point, trans individuals must pay for these treatments out-of-pocket, meaning that most people cannot access them. While the question of medicalization differs somewhat for trans and gender-nonconforming individuals than for LGBQ individuals, there is still a great stake in establishing relationships with biomedical establishments that begin from a point of self-determination rather than coercion. So long as health, epidemiologic, and pharmacologic research takes for granted the process by which trans and gender-nonconforming people are positioned within biomedicine, these important sources of ill health will not enter or be analyzed within the body of knowledge dealing with the health and wellbeing of trans and gender-nonconforming communities.

A third caution when considering trans inclusion in research concerns the very practice of "counting" trans and gender-nonconforming individuals

and quantifying disease burdens within this group. A variety of scholars have argued that statistical data gathering is an instrument of population management. As Ian Hacking argues, statistics are grounded in "the notion that one can improve—control—a deviant subpopulation by enumeration and classification."[88]

Deborah Lupton paraphrases Michel Foucault in discussing the emergence of "medico-administrative" knowledge. Medicine, she writes:

> [B]ecame a "general technique of health" and not simply a means of ministering to or curing the ill. Medicine was enfolded within a system of administration, rendered part of the machinery of power, serving as the core of the "social economy." As part of these changes, "population" becomes constituted as a problem, a target for surveillance, regulation, analysis, and intervention."[89]

In combination with medicine's historical pathologization of difference, these histories offer a cautionary message about the potential consequences of pursuing health-based surveillance of trans communities.

Finally, the last question to consider is the ways in which, particularly with regard to state-based health research, inclusion in research is tied to a notion of citizenship (this has been referred to as "biomedical" or "biopolitical" citizenship).[90] The liberal, rights-based strategies that national LGBTQ organizations have taken on in the last decade as priorities and which center on legislative campaigns and foreground issues such as gay marriage, hate crimes legislation, and inclusion in the military have been critiqued for their move toward incorporation within, rather than resistance to, state-sanctioned institutions.[91] LGBTQ health advocacy has, in large part, paralleled this, departing from the previous distrust with which federal institutions such as the DHHS, the NIH, and the CDC were viewed, there is now an urgent call to be considered, incorporated by and studied by these institutions. Once again, given the ways in which state-based institutions have been severe sources of coercion and violence for trans and gender-nonconforming communities, an overreaching and uncritical desire for

incorporation within this biomedical framework should be considered suspect.

Some health and epidemiologic researchers have called into question both the drive toward incorporation and the validity of the "expert/layperson" divide. Community-based participatory research (CBPR), an orientation toward research that values non-academic community members as instrumental to framing research questions, conducting research, and disseminating findings[92] have been used in a variety of health studies to establish understanding of local knowledge[93] about health and wellbeing. Duran and Wallerstein discuss some of the ways in which research with this orientation may resist pervasive assumptions about traditional health and epidemiologic research: CBPR is "openly emancipatory research, which challenges the colonizing practices of positivist research and political domination by the elites."[94] Several important studies, some of which are ongoing,[95] have taken this approach to health research. This may be a productive site for future investigations of health disparities within these communities that transcend those constrained by state-based agendas.

As with the AMA resolution, some kinds of health research may help to generate more options for trans people. In continuing this work, however, it is critical to consider the ways in which benefits will or will not be equitably distributed across trans and gender-nonconforming communities. Departing from the dominant health research agendas of the state might present a set of different challenges, but it might enable us to document a broader and more comprehensive understanding of the factors underpinning trans and gender-nonconforming health in the United States.

V. HEALTH RESEARCH AND "LOOPING EFFECTS"

Another consideration in evaluating trans inclusion in research—albeit a slightly more abstract one—is how people respond to the ways in which they are categorized. Ian Hacking comments that

> [W]e tend to behave in the ways that are expected of us, especially by authority figures—doctors, for example. . . . People classified in a certain way tend to conform to or grow into the ways that they are described; but they also evolve in their own ways, so that the classifications and descriptions have to be constantly revised.[96]

This matters because health research plays a part in the way we, as trans and gender-nonconforming people, see ourselves. Although this is not, as Hacking importantly emphasizes, a one-way street, it is significant to examine the ways in which medicine and research contextualize—and in some ways define—our identities and experiences.

The concept of invisibility and erasure are consistent themes in the lives of many transgender and gender-nonconforming individuals, and the case of health is no exception. As part of the Trans PULSE community-based research project out of Ontario, Canada, researchers found that a particular theme that arose in qualitative research with trans community members about perceived barriers to health was the concept of "informational and institutional erasure."[97] This was reflected by institutions viewing trans health as anomalous and placing the onus of system navigation on trans individuals. Qualitative data reflected frustration with the lack of knowledge on the part of healthcare providers about the existence and needs of trans and gender-nonconforming individuals (informational erasure) and a lack of policies and documents, such as medical intake forms, that listed or acknowledged the possibility of trans and gender-nonconforming patients accessing services (institutional erasure).[98] Notably, while this research project holds in common certain findings as some of the needs assessments, it has uncovered a slightly different set of priorities than many health studies that concern trans and gender-nonconforming communities. It emphasizes administrative changes over formal legal changes, which departs from the standard rubric of state-based LGBTQ health.[99] In addition, in its qualitative methodological approach, it attends to the range of different needs that span trans and gender-nonconforming communities

and captures information about the lived realities of trans and gender-nonconforming individuals grappling with a concept of health and wellness through gender non-normative positionalities.[100]

Interestingly, the Trans PULSE study has also captured some of the ways in which trans people conceptualize themselves in and through research. In discussing informational erasure, which the authors argue includes the lack of research findings, one participant commented, "I'm one of the dead ones. Remember [this], just because you're [transsexual], you're one of the dead ones. All of this time that I've survived, I'm one of the walking dead because we're not counted; we're not represented anywhere."[101] This is quite a profound indication of the ways in which health research, healthcare delivery, medicalization, professionalization, political marginalization, and other factors have interacted to tether identity to surveillance, research, and representation.

Ian Hacking discusses the "looping effects of human kinds."[102] He more recently has referred to these as "interactive" kinds (contrasted with "indifferent" kinds).[103] He describes looping effects as the ways in which "human beings and human acts come into being hand in hand with our invention of the categories of labeling them."[104] These effects, he argues, come "from above" (or from experts who name and categorize humans) as well as "from below" (from those who are being named and categorized). In a variety of ways, this "conversation" can be observed within trans and gender-nonconforming communities to occur in the very negotiation of naming: even in the choice to spell "transexual" with a single "s." However, it seems that increasingly, trans and gender-nonconforming individuals are positioning ourselves within this conversation inside a framework of recognition and inclusion, and research seems not to be an exception.

Further, in understanding ourselves in and through bodies of traditional health and epidemiologic research, are we in danger of reducing our notion of ourselves, our health, and our wellbeing to disease risk and susceptibility to violence? Are we invoking a desire for better and nicer experts to manage

our existences and identities, or are we calling for a broader authority and weight of local and community-based knowledge? What is at stake in connecting the validation of existence to health surveillance? Are there ways that we might pursue knowledge about health and wellbeing in trans communities that is broader, more expansive, less tied to state interests, and more transformative in its potential for action and change? If so, how might we position our communities, inclusive and cognizant of the marked differences within them, to leverage our significant resilience and strength to gather this knowledge and find solutions to the issues that compromise and endanger our health and wellbeing?

CONCLUSION

Trans and gender-nonconforming people are clearly in need of better quality, more comprehensive, more affordable, and more supportive healthcare. A variety of factors, including biomedicine's reliance on evidence-based medicine in establishing public and private insurance coverage policies have made research an important pursuit. But a myopic and single-minded pursuit of health and epidemiologic research on trans and gender-nonconforming communities fails to take into account a number of important considerations.

First, there may be broader and more expansive ways to obtain these necessary changes, as through the transformation of the health system to provide universal access to healthcare inclusive of just and supportive gender-affirming care. Second, while health research itself is not a bad idea, a variety of features of the current frameworks of research (especially state-based research) invite thorough consideration of how trans and gender-nonconforming communities want to position ourselves within these frameworks. Third, if we continue to call for health and epidemiologic research within our communities, it will be crucial to attend to the ways in which relative access to privilege varies radically and to recognize that these differences profoundly shape health disparities *within* our

communities. Last, as we consider what changes in the status quo will improve health and wellbeing for trans and gender-nonconforming individuals, it is important to reflect on what is at stake in any of the courses of action that we may choose to take. Health research may be a component of this, but a departure from the course that LGBTQ health activism has taken will probably be of great benefit in the long run. Community engagement and local knowledge will likely strengthen and deepen the body of knowledge that we build with regard to health, and these are more likely to productively shape and mesh with existing community-based movements.

Let us develop ways to pursue health research that do not leave gaps in what we are permitted to know about ourselves. We will not gain access to knowledge that is sufficiently rich or robust if we only enlist "experts" to develop this knowledge and align ourselves with state agendas. An overreliance on professionalized expertise and state-based alignment will create a situation in which we are even less likely to attend to some of the central factors compromising health in trans and gender-nonconforming communities. Community-based participatory research is one way to structure research programs in a more inclusive and productive way. Developing and strengthening grassroots and community-based groups that are doing work that overlaps with or within trans and gender-nonconforming communities will help us continue to build on and share local knowledge and to create alliances with overlapping communities that may share similar barriers to health (individuals with disabilities, people of color, low-income people, etc.).

Although it is profoundly painful and frustrating to witness the continued marginalization of trans health within larger LGBTQ health advocacy, we may have been granted an opportunity to take a different direction in gathering knowledge and setting a distinct course in the pursuit of our health and wellbeing. Let us hope that our example will inspire others to follow.

[1] The author would like to extend special thanks to Elizabeth Payne and Dean Spade along with the editorial staff of the *Seattle Journal for Social Justice.*

[2] *See, e.g.*, Jae Sevelius, *"There's No Pamphlet for the Kind of Sex I Have": HIV-Related Risk Factors and Protective Behaviors Among Transgender Men Who Have Sex With Nontransgender Men*, 20 J. ASS'N NURSES AIDS CARE, 335, 398 (2009); Joseph P. De Santis, *HIV Infection Risk Factors Among Male-To-Female Transgender Persons: A Review of the Literature*, 20 J. ASS'N NURSES AIDS CARE 335, 362 (2009); Jeffrey H. Herbst et al., *Estimating HIV Prevalence and Risk Behaviors of Transgender Persons in the United States: A Systematic Review*, 12 AIDS BEHAV. 1, 1 (2008); Emilia L. Lombardi et al., *Gender Violence: Transgender Experiences With Violence and Discrimination*, 42 J. HOMOSEXUALITY 1, 1 (2002).

[3] *See generally* IAN HACKING, *The Looping Effect of Human Kinds*, *in* CAUSAL COGNITION: A MULTIDISCIPLINARY DEBATE 351 (Dan Sperber et al. eds., 1995).

[4] JULIA SERANO, WHIPPING GIRL: A TRANSSEXUAL WOMAN ON SEXISM AND THE SCAPEGOATING OF FEMININITY 115 (2007); Karl Bryant, *Making Gender Identity Disorder of Childhood: Historical Lessons for Contemporary Debates*, 3 SEXUALITY RESEARCH AND SOC. POL'Y 23–29 (2006).

[5] George J. Wilkerson, *What We Don't Know: The Unaddressed Health Concerns of the Transgendered*, TRANS-HEALTH, http://www.trans-health.com/displayarticle.php?aid=7 (last visited Feb. 19, 2010).

[6] Sevelius, De Santis, Herbst, Lombardi, *supra* note 1. Throughout the paper, I will employ the term "transgender," "trans," and "gender-nonconforming" to refer to individuals who vary from symmetrical arrangements of birth-assigned sex with dominant cultural expectations of gender expression. There is some necessary slippage and vagueness in the language here, which is the topic of many investigations about the category of "transgender" itself. See DAVID VALENTINE, IMAGINING TRANSGENDER: AN ETHNOGRAPHY OF A CATEGORY (2007) for one such exploration. As Valentine discusses, there is a tension within this term, as it is often externally applied to those who reject it or would not choose to apply it to themselves, as well as being a term that people use in various ways to self-identify. In addition, the inclusion of non-trans intersex people in the broad category "gender nonconforming" varies, depending greatly on the ways in which these individuals self-identify, seek services, or are extended membership by groups, organizations, and agencies. However, in the context of health research, there seems to be a fairly consistent divide between "transgender individuals" and "intersex individuals," despite the potential overlaps of the two.

[7] "Transsexuals" is a term I use in the context of this article only to capture dominant language used by medical and psychiatric researchers during this time. This term continues to be used in a variety of ways, both within the field of research (although, it would seem, to a far lesser degree than previously) and by people in trans communities, in general. Many trans individuals themselves spell the term with one "s" to resist the pathologizing legacy of the word, while others claim the term "transsexual" but not "transgender." VALENTINE, *supra* note 5 at 25–26.

[8] *See generally* HARRY BENJAMIN, THE TRANSSEXUAL PHENOMENON (1966).

[9] M. HIRSCHFELD, DIE INTERSEXUELLE KONSTITUTION JAHRBUCH FUER SEXUELLE ZWISCHENSTUFEN 23 (1923).
[10] *See, e.g.*, Greta R. Bauer et al., *"I Don't Think This Is Theoretical; This Is Our Lives": How Erasure Impacts Health Care for Transgender People*, 20 J. ASS'N NURSES AIDS CARE 335, 348 (2009); Kristin Clements-Nolle & Ari Max Bachrach, *Community-Based Participatory Research With a Hidden Population: The Transgender Community Health Project*, *in* COMMUNITY BASED PARTICIPATORY RESEARCH FOR HEALTH 332, 332 (Meredith Minkler & Nina Wallerstein eds., 2002); Jessica M. Xavier et al., *A Needs Assessment of Transgendered People of Color Living in Washington, D.C.*, 8 INT'L J. TRANSGENDERISM 1, 31 (2005).
[11] This is reflected both by the increased presence of trans and gender-nonconforming individuals who lead health research, but also by changes such as the recent inclusion of trans individuals on the board of bodies such as the World Professional Association for Transgender Health (WPATH, formerly the Harry Benjamin International Gender Dysphoria Association, or HBIGDA), that circulates the most broadly-circulated Standards of Care for trans patients seeking gender-related medical interventions.
[12] *See, e.g.*, GIANNA E. ISRAEL & DONALD E. TARVER, TRANSGENDER CARE: RECOMMENDED GUIDELINES, PRACTICAL INFORMATION, AND PERSONAL ACCOUNTS (1997).
[13] I use 'LGBT health' when 'queer' is not necessarily specifically implied. Generally, I use "LGBTQ" to include queer-identified individuals, as well. Acronyms that are inclusive of two-spirit individuals, intersex individuals, individuals who identify as same-gender-loving, people who are questioning their sexuality, and others are also frequently included in acronyms to generally describe these communities.
[14] Steven Epstein, *Sexualizing Governance and Medicalizing Identities: The Emergence of 'State-Centered' LGBT Health Politics in the United States*, 6 SEXUALITIES 135 (2003).
[15] STEVEN EPSTEIN, IMPURE SCIENCE: AIDS, ACTIVISM, AND THE POLITICS OF KNOWLEDGE 32–33 (1996).
[16] Epstein, *supra* note 13, at 138–41.
[17] *Id.* at 139.
[18] *Id.* at 141.
[19] *Id.*
[20] For a discussion of health disparities as a frame in the context of discussions about health, see Nancy Krieger et al., Painting a Truer Picture of US Socioeconomic and Racial/Ethnic Health Inequalities: The Public Health Disparities Geocoding Project, 95 AM. J. OF PUB. HEALTH 312 (2005).
[21] GAY AND LESBIAN MEDICAL ASS'N & LGBT HEALTH EXPERTS, HEALTHY PEOPLE 2010 COMPANION DOCUMENT FOR LESBIAN, GAY, BISEXUAL, AND TRANSGENDER (LGBT) HEALTH (2001) [hereinafter 2010 COMPANION DOCUMENT FOR LGBT].
[22] Epstein, *supra* note 13.
[23] *Id.* at 151.
[24] 2010 COMPANION DOCUMENT FOR LGBT, *supra* note 20.
[25] Katherine L. Turner et al., *Lesbian, Gay, Bisexual, and Transgender Cultural Competency for Public Health Practitioners*, *in* THE HANDBOOK OF LESBIAN, GAY,

BISEXUAL, AND TRANSGENDER PUBLIC HEALTH: A PRACTITIONER'S GUIDE TO SERVICE 59, 60 (Michael D. Shankle ed., 2006).
[26] Epstein, *supra* note 13, at 159.
[27] *Id.*
[28] Emily Douglas, *An Uneasy Alliance*, AM. PROSPECT, Nov., 2008, at 30.
[29] *Id.*
[30] Rickke Mananzala & Dean Spade, *The Nonprofit Industrial Complex and Trans Resistance*, 5 SEXUALITY RESEARCH & SOC. POL'Y 53, 53 (2008).
[31] JESSICA XAVIER ET AL., NATIONAL COALITION FOR LGBT HEALTH, AN OVERVIEW OF US TRANS HEALTH PRIORITIES: A REPORT BY THE ELIMINATING DISPARITIES WORKING GROUP (Aug., 2004), *available at* http://www.lgbthealth.net/downloads/research/US_Trans_Health_Piorities.pdf.
[32] The World Health Organization defines global burden of disease to be a "time-based measure" that "combines years of life lost due to premature mortality and years of life lost due to time lived in states of less than full health." World Health Organization, Global Burden of Disease, www.who.int/topics/global_burden_of_disease/en/ (last visited Feb. 17, 2010).
[33] XAVIER ET AL., *supra* note 31, at 3-4.
[34] XAVIER ET AL., *supra* note 31, at 3.
[35] XAVIER ET AL., *supra* note 31, at 3.
[36] *See, e.g.*, WALTER BOCKTING & ERIC AVERY, TRANSGENDER HEALTH AND HIV PREVENTION: NEEDS ASSESSMENT STUDIES FROM TRANSGENDER COMMUNITIES ACROSS THE UNITED STATES (2005); Gretchen P. Kenagy, *Transgender Health: Findings From Two Needs Assessment Studies in Philadelphia*, 30 HEALTH & SOC. WORK 19, 19 (2005); Xavier, *supra* note 9.
[37] *See generally* 2010 COMPANION DOCUMENT FOR LGBT, *supra* note 20; XAVIER ET AL., *supra* note 31.
[38] *See generally* Meredith Minkler & Nina Wallerstein, *Introduction to Community Based Participatory Research*, *in* COMMUNITY BASED PARTICIPATORY RESEARCH FOR HEALTH, 3–5 (Meredith Minkler & Nina Wallerstein eds., 2002); Kristen Clements-Nolle et al., *HIV Prevalence, Risk Behaviors, Health Care Use, and Mental Health Status of Transgender Persons: Implications for Public Health Intervention*, 91 AM. J. PUB. HEALTH 915 (2001); Bauer et al., *supra* note 9.
[39] For example, the UCSF Center of Excellence on Transgender HIV prevention became the Center of Excellence in Transgender Health in 2009. The precise co-occurrence of HIV/AIDS epidemiologic research and transgender health is more complicated than may be attended to in the context of this article. It is, to the author's knowledge, unclear whether HIV/AIDS prevention gained centrality as a topic because HIV/AIDS research has focused on marginalized groups, or because needs assessment studies repeatedly found such high incidence and prevalence rates of HIV/AIDS, as asserted in Xavier, *supra* note 9, and Bockting & Avery, *supra* note 36, that resources and attention have been consolidated in the arena. Regardless of the particularities, HIV/AIDS prevention and epidemiologic research is frequently intertwined with discussions of trans health.
[40] Ethan Jacobs, *Collection of Trans HIV Data Slow*, BAY WINDOWS ONLINE (June 26, 2008), http://www.baywindows.com/index.php?ch=news&sc=glbt&sc2=news&sc3

=&id=76431; SAN FRANCISCO AIDS FOUNDATION, TRANSGENDER PERSONS AND HIV, HIV EVIDENCE REPORT (Jan. 2009), http://www.sfaf.org/files/site1/asset/sfaf-hiv-evidence-report-jan-2009.pdf.

[41] Edward H. Kaplan & Michael H. Merson, *Allocating HIV-Prevention Resources: Balancing Efficiency and Equity*, 92 AM. J. PUB. HEALTH 1905 (2002).

[42] Jordan Blaza & Elizabeth Mediano, Asian Pacific AIDS Intervention Team, Los Angeles, CA, Transgender Program for Excellence: HIV Prevention and Community Education, Presentation at the 2003 National HIV Prevention Conference (July 28, 2003) (abstract available at http://gateway.nlm.nih.gov/MeetingAbstracts/ma?f=102262202.html) (focusing on M-T-F individuals).

[43] *See, e.g.*, Rita M. Melendez & Rogerio M. Pinto, *HIV Prevention and Primary Care for Transgender Women in a Community-Based Clinic*, 20 J. ASS'N NURSES AIDS CARE, 335, 387 (2009); *see generally* BOCKTING & AVERY, *supra* note 36; De Santis, *supra* note 1; Kenagy, *supra* note 36; Sari Resiner et. al., *HIV Risk and Social Networks Among Male-to-Female Transgender Sex Workers in Boston, Massachusetts*, 20 J. ASS'N OF NURSES AIDS CARE 373 (2009).

[44] Clements-Nolle & Bachrach, *supra* note 9.

[45] *See, e.g.*, Bauer et al., *supra* note 9; Clements-Nolle & Bachrach, *supra* note 9.

[46] INCITE! WOMEN OF COLOR AGAINST VIOLENCE, THE REVOLUTION WILL NOT BE FUNDED: BEYOND THE NON-PROFIT INDUSTRIAL COMPLEX 1–8 (2007).

[47] JENNIFER R. WOLCH, THE SHADOW STATE: GOVERNMENT AND VOLUNTARY SECTOR IN TRANSITION (1990).

[48] INCITE!, *supra* note 46, at 8–9.

[49] Ruth Gilmore, *In the Shadow of the Shadow State*, *in* THE REVOLUTION WILL NOT BE FUNDED: BEYOND THE NON-PROFIT INDUSTRIAL COMPLEX 49 (Incite! Women of Color Against Violence eds., 2007) (discussing the Pacifica Radio being a listener-sponsored organization that created a national board under the pressures to "professionalize"); Alisa Bierria, *Pursuing a Radical Anti-Violence Agenda Inside/Outside a Non-Profit Structure*, *in* THE REVOLUTION WILL NOT BE FUNDED: BEYOND THE NON-PROFIT INDUSTRIAL COMPLEX 151 (Incite! Women of Color Against Violence eds., 2007).

[50] Gilmore, *supra* note 49, at 47.

[51] *See* Lisa Duggan, THE TWILIGHT OF EQUALITY?: NEOLIBERALISM, CULTURAL POLITICS, AND THE ATTACK ON DEMOCRACY at xvii–xx, 9–11 (2003).

[52] Mananzala & Spade, *supra* note 29, at 55–56.

[53] STEVEN EPSTEIN, INCLUSION: THE POLITICS OF DIFFERENCE IN MEDICAL RESEARCH 264 (2007).

[54] *Removing Financial Barriers to Care for Transgender Patients: Hearing on Res. 122 Before the American Medical Association H.D.* (2008). It is important to note that prior to acceptance of this resolution, the AMA House of Delegates decided on Resolution 122 Removing Financial Barriers to Care for Transgender Patients, rather than Resolution 114 Removing Barriers to Care for Transgender Patients, or Resolution 115 Removing Insurance Barriers to Care for Transgender Patients. In addition, amendments were made to the resolution to include language stipulating physicians' involvement in the assessment and determination of treatment of gender identity disorder.

[55] This navigation is required of trans and gender-nonconforming people whether or not they desire gender-confirming medical intervention, as those who do not must still access

primary care or attempt to get a legal identification, for example, in a system that is reliant on a medicalized proof of identity.

[56] XAVIER, *supra* note 31, at 2.

[57] Dean Spade, *Transformation: Three Myths Regarding Transgender Identity Have Led to Conflicting Laws and Policies that Adversely Affect Transgender People*, 31 L.A. LAWYER 38–39 (2008).

[58] Walter Bockting, *Transgender HIV Prevention: A Qualitative Needs Assessment*, 10 AIDS CARE 505–25 (1998); *see generally* Kenagy, *supra* note 36; Xavier et al., *supra* note 9.

[59] For example, the high HIV incidence and prevalence rates that smaller-scale studies have found have been used to justify a need to fund and create transgender-specific HIV prevention and programming. *See, e.g.*, Jae Sevelius et al., Center for Excellence for Transgender HIV Prevention, *Serving Transgender People in California: Assessing Progress, Advancing Excellence* 8 (2008), http://transhealth.ucsf.edu/pdf/serving-trans-ca.pdf.

[60] *See generally* VALENTINE, *supra* note 5.

[61] Nancy Krieger, *Questioning Epidemiology: Objectivity, Advocacy, and Socially Responsible Science*, 89 AM. J. PUB. HEALTH 1151, 1152 (1999).

[62] Marj Plumb, *Undercounts and Overstatements: Will the IOM Report on Lesbian Health Improve Research?*, 91 AM. J. PUB. HEALTH, 873, 874 (2001).

[63] DEBORAH LUPTON, RISK 99 (1999).

[64] EPSTEIN, *supra* note 53, at 291.

[65] U.S. Food and Drug Administration, Blood Donations from Men Who Have Sex with Other Men Questions and Answers, http://www.fda.gov/biologicsbloodvaccines/bloodbloodproducts/questionsaboutblood/ucm108186.htm (last visited Mar. 4, 2010).

[66] There are some exceptions to this, some of which I discuss later in the context of community-based research. Generally, trans health research, particularly as it is positioned within broader LGBTQ health activism agendas, largely fails to engage with these, or does so in a way that presumes "competency" issues are at the root rather than structural ones.

[67] A search in PubMed, http://www.nci.nlm.nih.gov/pubmed, yielded ninety-eight results for the concurrent terms "transgender" and "HIV" in the title or abstract of articles. Another search yielded twenty-seven results for "transgender" and "violence." Of these twenty-seven, abstracts generally described "violence" as "domestic violence," "sexual violence," "intimate partner violence," "harassment and discrimination," "assaults," "violence in their homes," and others. While at least some of these did not necessarily exclude the described acts of violence from occurring in an institutional setting, very few made explicit mention of state employees or institutions, and none made explicit mention of institutional violence or violence by police, prison staff, group home staff and so on.

[68] INCITE! WOMEN OF COLOR AGAINST VIOLENCE, LAW ENFORCEMENT VIOLENCE AGAINST WOMEN OF COLOR & TRANSGENDER PEOPLE OF COLOR: A CRITICAL INTERSECTION OF GENDER VIOLENCE & STATE VIOLENCE 25-28, *available at* http://www.incite-national.org/media/docs/3696_TOOLKIT-FINAL.pdf.

[69] *Matthew Shepard Hate Crimes Prevention Act Clears Key Senate Hurdle*, HUMAN RIGHTS CAMPAIGN, July 16, 2009, http://www.hrc.org/13187.htm.

[70] blackandpink.org: A Compilation of Critiques on Hate Crimes Legislation, http://www.blackandpink.org/revolt/a-compilation-of-critiques-on-hate-crimes-legislation/ (last visited Feb. 19, 2010).
[71] Robert Pear, *Doctors' Group Opposes Public Insurance Plan*, N.Y. TIMES, June 11, 2009, at A11.
[72] *See generally* Mananzala & Spade, *supra* note 29.
[73] LISA MOTTET & JOHN OHLE, NAT'L GAY AND LESBIAN TASK FORCE POL'Y INST., TRANSITIONING OUR SHELTERS 32–34 (2003).
[74] EPSTEIN, *supra* note 53, at 270.
[75] *Id.* at 17.
[76] *Id.* at 293–96.
[77] *See* Janet K. Shim, *Constructing Race Across the Science-Lay Divide: Racial Formation in the Epidemiology and Experience of Cardio Vascular Disease*, 35 SOC. STUD. SCI. 405, 412 (2005).
[78] *See id.*
[79] *See generally* Kimberle Crenshaw, *Mapping the Margains: Intersectionality Identity Politics and Violence Against Women of Color*, *in* THE PUBLIC NATURE OF PRIVATE VIOLENCE 93 (Martha Fineman & Roxanne Mykitiuk eds., 1994); EPSTEIN, *supra* note 53.
[80] EPSTEIN, *supra* note 53.
[81] *See* Lisa F. Berkman & Ichiro Kawachi, *A Historical Framework for Social Epidemiology*, *in* SOCIAL EPIDEMIOLOGY 3, 7–8 (Lisa F. Berkman & Ichiro Kawachi eds., 2000); N. Krieger, *A Glossary for Social Epidemiology*, 55 J. EPIDEMIOLOGY AND COMMUNITY HEALTH 693, 695–99 (2001); Ana V. Diez-Roux, *Bringing Context Back Into Epidemiology: Variables and Fallacies in Multilevel Analysis*, 88 AM. J. PUB. HEALTH 216, 216–17 (1998); Margaret W. Leung et al., *Community-Based Participatory Research: A Promising Approach for Increasing Epidemiology's Relevance in the 21st Century*, 33 INT'L J. EPIDEMIOLOGY 499, 499–504 (2004).
[81] Plumb, *supra* note 63, at 874.
[82] Leung et al., *supra* note 82, at 502.
[83] Medicalization and de-medicalization are frequent themes in the sociology of health and medicine. *See* PETER CONRAD, THE MEDICALIZATION OF SOCIETY: ON THE TRANSFORMATION OF HUMAN CONDITIONS INTO TREATABLE 4 (2007). However, a variety of interesting critiques of an orthodox concept of "medicalization" as a critique have arisen in the last decade. Deborah Lupton, *Foucault and the Medicalisation Critique*, *in* FOUCAULT, HEALTH AND MEDICINE 94–97 (Alan Petersen & Robin Bunton eds., 1997); Nikolas Rose, *Beyond Medicalisation*, 369 LANCET 700, 700–02 (2007). Although I will not explore these themes in this essay, these explore compelling themes in complicating a critique of the role of medicine beyond a concept of "medicalization," and in doing so emphasize the futility of "de-medicalization" as a pursuit, and consider the active and significant role of the patient in returning the clinical gaze. Regardless of these critiques, for the purposes of this paper, I use the term "medicalization" to critique the role of medicine in its coercive and restrictive management of gender nonconformity.
[84] Epstein, *supra* note 13, at 160.
[85] Dean Spade, *Compliance is Gendered: Struggling for Gender Self-Determination in a Hostile Economy*, *in* TRANSGENDER RIGHTS 229 (Paisley Currah et al. eds.) (2006).

[86] Spade, *supra* note 57, at 37–38.
[87] THE HARRY BENJAMIN INTERNATIONAL GENDER DYSPHORIA ASSOCIATION'S STANDARDS OF CARE FOR GENDER IDENTITY DISORDERS 20–21 (6th ed. 2001).
[88] IAN HACKING, THE TAMING OF CHANCE 3 (1990).
[89] DEBORAH LUPTON, THE IMPERATIVE OF HEALTH: PUBLIC HEALTH AND THE REGULATED BODY 23 (*quoting* MICHEL FOUCAULT, *The Politics of Health In the Eighteen Century*, *in* THE FOUCAULT READER 278 (Pantheon Books 1984)).
[90] NIKOLAS ROSE, THE POLITICS OF LIFE ITSELF: BIOMEDICINE, POWER, AND SUBJECTIVITY IN THE TWENTY-FIRST CENTURY 146 (2007); EPSTEIN, *supra* note 53, at 21.
[91] *See generally* TRANSGENDER RIGHTS (Paisley Currah et al. eds.) (2006); Manazala & Spade, *supra* note 29.
[92] *See, e.g.*, Clements-Nolle & Bachrach, *supra* note 9.
[93] Various definitions of "local knowledge" exist. Lindblom and Cohen describe a "knowledge that does not owe its origin, testing, degree of verification, truth status, or currency to distinctive . . . professional techniques but rather to common sense, casual empiricism, or thoughtful speculation and analysis." CHARLES E. LINDBLOM & DAVID K. COHEN, USABLE KNOWLEDGE: SOCIAL SCIENCE AND SOCIAL PROBLEM SOLVING 12 (1979).
[94] Minkler & Wallerstein, *supra* note 38, at 28.
[95] *See, e.g.*, Bauer et al., *supra* note 9; Clements-Nolle & Bachrach, *supra* note 9.
[96] IAN HACKING, REWRITING THE SOUL: MULTIPLE PERSONALITY AND THE SCIENCES OF MEMORY 21 (1995).
[97] Bauer et al., *supra* note 9, at 356.
[98] *Id.* at 352–56.
[99] *Id.* at 357–59.
[100] *Id.*
[101] *Id.* at 352.
[102] *See* HACKING, *supra* note 2.
[103] IAN HACKING, THE SOCIAL CONSTRUCTION OF WHAT? 103–06 (1999).
[104] Ian Hacking, *Making Up People*, *in* THE SCIENCE STUDIES READER 161, 170 (Mario Biagioli ed., 1999).